

Testimony
Public Health Committee
Bill 7376, An Act Establishing the Connecticut Health Information Network
March 14, 2007

Good morning/afternoon, Senator Handley, Representative Sayers and members of the Public Health Committee. My name is Eileen Storey. I am the Co-Director of the Center for Public Health and Health Policy at the University of Connecticut Health Center. I am here today to testify in support of Raised Bill 7376, An Act Establishing the Connecticut Health Information Network. The Center on Public Health and Health Policy was established in 2004 to serve as the central force in organizing public health teaching, research, and service to the community within the University of Connecticut. The Center allows the University to speak with one voice regarding critical needs in public health education and research for all of our citizens throughout the State and the region. One of our first priorities has been to investigate the need for an integrated health database in Connecticut and to explore potential solutions to the unique challenges facing Connecticut in this area.

For the past 3 years, we have been working to develop what we have called the CT Health Information Network, or CHIN. CHIN is a partnership between the Health Center and a number of state agencies to develop a federated computer network linking disparate health databases across these agencies and the Health Center. CHIN will provide agencies, health researchers, policymakers, and other stakeholders the ability to access health information that is currently difficult to procure. It will provide opportunities to assess target populations and track their interactions across state agencies over time. It will advance evidence-based practices by linking programs and interventions with health outcomes. It will encourage and facilitate the development of uniform data standards across agencies. It is an important tool for achieving results-based accountability. In addition, it can serve as a platform to provide important public health information to consumers in a user-friendly format.

CHIN is a federated, or distributed, network. This means that agency databases stay where they are and continue to operate as they always have. CHIN's software and middleware would access databases in real time and identify individual files that match a specific query. CHIN then uses probabilistic algorithms to match files in different databases, strips personal identifiers from the data, and issues de-identified data to the requester. There is no need to build an expensive central data warehouse, or to risk losing data as it is migrated to a new system. There is no need to train staff to operate new data systems within each agency, and there is minimal impact on the agencies' IT staff or budgets.

CHIN is being developed by the Health Center in partnership with AKAZA, Inc of Cambridge, MA, and up to now the Health Center has funded its initial development. It is being developed as an open-source technology, meaning that it will not be proprietary and can be freely disseminated. Raised Bill 7379 will provide important support and funding to allow the development of CHIN to continue. We are currently piloting a prototype of the network and are ready to move beyond the initial pilot phase into actual network development, but this is beyond the ability of the Health Center to fund out of existing moneys.

Raised Bill 7376 will also remove some of the legal obstacles that have hampered agencies' ability to participate in the development of CHIN. Existing state confidentiality laws are scattered across the CT General Statutes and are inconsistent in their restrictions on the disclosure of information for research purposes. In some instances, agencies cannot even share information with each other for case management or program evaluation without elaborate MOAs. RB 7376 clarifies the application of these statutes to CHIN and allows agencies to release identified information to CHIN for the purposes of matching and aggregation, but restricts the ability of CHIN to re-disclose such information in personally identifiable form, thus protecting the confidentiality of personal health data. As a HIPAA Covered Entity, the Health Center is subject to HIPAA privacy and security requirements, and these important safeguards will apply to CHIN's administrators within the Health Center.

Under the proposed bill, CHIN will not be owned by the Health Center or the University. We will be the administrators, but access to the network will be governed by a collaborative board composed of representatives from the participating agencies, as well as gubernatorial and legislative appointees representing local public health departments, other health data users, and consumers. It will be developed in collaboration with DOIT and the participating agencies. It will be developed with the capability of future expansion to other agencies and non-governmental databases.

In bringing this to you, we recognize that this is a critical priority for the State, and that the University has the scientific and technical expertise to make this a reality. However, the development of CHIN goes above and beyond the academic and research mission of the Schools of Medicine and Dental Medicine. This bill should reflect that this appropriation is separate from any funding the Health Center receives for its core mission, and that the development and implementation of CHIN is dependent on the funding provided in this bill.

We look forward to working with the Committee to address any concerns you may have as you move forward with this proposed legislation. We are happy to answer any questions you may have, and thank you for taking up this important concept.

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